

UNDERSTANDING DISABILITIES WITHIN SIBLING RELATIONSHIPS THROUGH
EMERGING ADULTHOOD

by

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Sibling relationships, one of the most important relationships an individual can have, plays a significant role during childhood, adolescence, and adulthood. To properly comprehend how siblings can impact one another, the current study examined how disabilities impact sibling relationships during emerging adulthood. The primary purpose of this study is to examine the positive aspects of sibling relationships when one sibling has a disability. The second purpose is to contribute to previous literature by using a self-perspective lens on the experience through the lens of an emerging adult. Through a mixed methods approach, results showed that childhood sibling relationships have a significant direct impact on sibling relationships during adulthood. However, there was not a direct relationship between demographics in both childhood and adulthood relationships. After analyzing the opened questions, most of the participants agreed that they gained positive aspects and experiences from their sibling with a disability.

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CHAPTER 1: INTRODUCTION

Sibling relationships, one of the most important relationships an individual has, can play a significant role during childhood, adolescence, and adulthood. During both childhood and adolescence, siblings directly influence one another's behavior and socioemotional development and adjustment (McHale et al., 2012). During adulthood the sibling relationship can be impacted as each young adult sibling grows to be more independent and moves out of their family home (Jensen et al., 2018). For example, there is a decrease in sibling contact during the transition of adulthood, which can have a negative impact on the sibling relationship quality (Jensen et al., 2018). To properly comprehend how siblings can impact one another is important, as 90% of the world's population has at least one sibling (Allison & Campbell, 2015). The different forms of sibling relationships—biological, adoptive, step, half, or foster—have the potential to influence many aspects of an individual's life (Allison & Campbell, 2015). For example, contextual factors, such as social interactions with friends in early childhood, can predict how siblings interact with each other (Kramer & Kowal, 2005; McHale et al., 2012).

Previous research on siblings demonstrates how disability can impact the relationship. During childhood, the overall physical and mental health of the sibling without disabilities can likely decrease (Marquis, Hayes, & McGrail, 2019a; Marquis, McGrail, & Hayes, 2019b). During emerging adulthood, the physical closeness will decrease while the emotional closeness will increase (Aldrich et al., 2021). The mental health of an individual who has a sibling with a disability can decrease throughout the lifespan (Sommantico et al., 2019). These aspects of having a sibling with a disability, effects the relationship during both childhood and emerging adulthood.

The CDC (2020) defines disability as “any condition of the body or mind impairment that makes it more difficult for the person with the condition to do certain activities and interacts with the world around them” (para. 1). There are several domains of life that can be impaired because of disability such as vision, movement, thinking, remembering, learning, communicating, hearing, mental health, and social relationships (CDC, 2020). The most common disability diagnoses include Attention-Deficit/ Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Cerebral Palsy, Intellectual Disability, Spina Bifida, and Fetal Alcohol Spectrum Disorders (FASD) (CDC, 2020). In the United States, approximately one in every four children are diagnosed with a disability (CDC, 2020).

Research has often focused on the parental perspective and challenging aspects of having a child with a disability. For example, Dodd (2004) highlighted that in the 1970s, research tended to emphasize the drawbacks of being a sibling to a disabled person. With little research on the positive impacts of having a sibling with a disability and research only using perspective of parents to examine sibling relationships (Carter et al., 2015), the current study focused on the self-perspective lens of the sibling without the disability and how disability can positively impact them in their sibling relationships.

Three research questions guide this study: (a) How does having a sibling with a disability during childhood predict the sibling relationship during emerging adulthood based on the Lifespan Sibling Relationship Scale? (b) How does demographic factors (*e.g.*, birth order, gender, race) influence sibling relationships when one has a disability? and (c) What are the positive aspects of having a sibling with a disability.

CHAPTER 2: LITERATURE REVIEW

Two major themes emerge when examining the literature on sibling relationships and the impact of a sibling with a disability. First, sibling relationships develop throughout the lifespan and can shift during childhood through emerging adulthood. Second, disability can impact each sibling individually and within the relationship. Many dimensions exist in sibling relationships and disability can impact the relationship in a manner that is both positive and challenging.

Sibling Relationship Development

Throughout Childhood and Adolescence

Sibling relationships are the most stable throughout childhood (Kramer & Kowal, 2005). Kramer and Kowal (2005) found that during early childhood, sibling relationships are reciprocal, where one sibling can affect the other and vice versa. They also found that some contextual factors, such as age, can impact this relationship. A larger age gap between the first and second-born can have a greater impact on the relationship. Older siblings have more influence on the younger sibling, but younger siblings can also impact how the older sibling development well (Kramer & Kowal, 2005).

Age is not the only factor that can impact the sibling relationship. Social interactions with friends in early childhood can predict how siblings interact with each other (Kramer & Kowal, 2005; McHale, et al., 2012). When the older sibling interacted with friends positively, there was a more positive interaction with their younger sibling (Kramer & Kowal, 2005). Positive sibling relationships can impact the psychological well-being of each child in that relationship and can affect how they deal with externalizing behaviors (Kramer & Kowal, 2005). If the firstborn has positive relationships with their friends, then that gives them the ability to express externalizing

behaviors, which can have a positive impact on their relationship with their sibling with a disability (Kramer & Kowal, 2005). Children who demonstrated low warmth, hostility, and low involvement showed that the other sibling will have higher levels of externalizing behaviors (Kramer & Kowal, 2005).

Different contextual factors can impact childhood relationships, such as sociocultural factors and family dynamics. McHale et al. (2012) noted that family dynamics can impact sibling relationships in childhood. They also noted that parental relationship quality, when the parents are either divorced, single-parent, and married dyads (a group of two people), can have an impact on the sibling relationships of their children. For example, when there is marital conflict in the family, there is an increase in sibling conflict which can impact the overall relationship quality. Furthermore, when parents are divorced it can result in more negativity and conflict in sibling relationships than when the parents were married. Based on McHale et al (2012) research parents' relationship directly influences sibling relationships quality.

McHale et al. (2012) research expands on how sociocultural factors, such as race and religion, impact sibling relationships. Established in their research, being in a minority or diverse family seems to impact sibling relationships as much as parental relationship quality. Exemplified in the research, there is a higher risk for girls in Latinx and Black/African American families to become mothers during adolescence. Furthermore, religion and spirituality of minority families has a positive impact sibling relationship quality.

From early childhood through adolescence, sibling relationships change and become more bi-directional (Brody, 2004; McHale et al., 2012). In early childhood, siblings showed more warmth, but during adolescence, siblings have increased conflict (McHale et al., 2012). Throughout adolescence, siblings can impact more risky behaviors for their siblings. Older

siblings are more likely to influence younger siblings' behaviors during adolescents than in childhood. For example, research shows that among poor, rural, African American families, the older sibling's problematic behaviors predict the younger sibling's behaviors (McHale et al., 2012). Older sibling can also have a positive effect of their younger siblings (Brody, 2004; Oliva & Arranz, 2004). Brody (2004) established that the older sibling can improve the younger sibling's cognitive development. Additionally, Oliva & Arranz (2005) research indicated that the older sibling can also guide the socio-emotional development of the younger sibling during adolescence.

Emerging Adulthood Transition

Sibling relationships shift to a matter of choice during emerging adulthood due to moving out of their childhood home (Jensen, Whiteman, & Fingerman, 2018). Multiple researchers reported that emerging adults reported having less sibling contact, but an increase in closeness (Jensen et al., 2018; Aldrich, Nomaguchi, & Fetro, 2021). During this transition, siblings have less conflict due to the decrease of time spent with each other (Jensen et al., 2018). A decrease in closeness could be attributed to adult siblings trying to find their independence (Jensen et al., 2018). Adult siblings report sharing more emotional and personal issues with their siblings than in adolescence (Aldrich et al., 2021).

During transition times, such as moving out of their childhood home, siblings reported an increase in closeness and a decrease in conflict (Jensen et al., 2018; Aldrich et al., 2021). On the contrary, emerging adults state that staying in their childhood homes did not change their sibling relationship quality, there was still a high level of conflict (Jensen et al., 2018). The high level of conflict could be due to how emerging adults view their transition into adulthood. If emerging

adults feel “stuck,” during this transition, then that can result in a strain on the sibling relationship (Jensen et al., 2018).

During emerging adulthood, there are developmental tasks that individuals are exploring, like furthering their career path, exploring higher education, having a relationship or life partner, or becoming a parent, which can all impact the sibling relationship. Aldrich et al. (2021) explained that while exploring higher education, new social groups are formed which negatively impact sibling relationships, because the sibling is spending more time with the new friends. On the other hand, they stated it can provide opportunities for the sibling to become closer, it gives siblings a chance to be able to talk more about social topics and share the new topics they are learning in college. The same is true with employment, as it can positively or negatively impact sibling relationships. Trying to balance work and personal life can harm the sibling relationship, due to the emerging adult focusing on themselves and their careers. On a positive note, emerging adults can afford resources, like phones, cars, and the internet to communicate with their siblings, which has a positive impact on the relationship. When it comes to being in a relationship or having a romantic life partner, siblings reported still having emotional closeness with their sibling, even with less physical contact. This result is the same if the emerging adult is becoming a parent. Overall, during emerging adulthood the sibling relationship shifts and changes.

Disability and Sibling Relationship

Throughout Childhood

More research has examined the health of the sibling who is impacted by disability. First, when examining the impact disability has on the psychological well-being of the non-disabled sibling, there is a negative correlation between low-income and the health and mental health of

the sibling without the disability (Marquis, Hayes, & McGrail, 2019a; Marquis, McGrail, & Hayes, 2019b). Children with a disability and their siblings in a single-parent home are more likely to be a low-income family (Marquis et al., 2019a). Low-income households have fewer resources for mental health, which is why children with a sibling who has a disability are at a higher risk of getting diagnosed with a mental disorder (Marquis et al., 2019a). Children who have siblings with a developmental disability have higher odds of getting diagnosed with depression (Marquis et al., 2019a). Research has shown that specifically, siblings of children with ASD (autism spectrum disorder) may have greater psychological and adjustment problems than siblings of children with other types of intellectual developmental disabilities (Marquis et al., 2019b).

Second, the health of the non-disabled sibling is just as important as the psychological well-being (Moyson & Roeyers, 2012). Moyson and Roeyers (2012) looked at the quality of life of children who have a sibling with a developmental disability. The non-disabled child was able to describe the discrepancy between what they could do with their disabled sibling and what they wanted to do (Moyson & Roeyers, 2012). The children described nine different domains of quality life as: (a) including joint activities (b) mutual understanding (c) private time (d) acceptance (e) forbearance (f) trust in well-being (g) exchanging experiences (h) social support and (i) dealing with the world (Moyson & Roeyers, 2012). For example, when it came to describing joint activities, the siblings talked about being able to participate in different activities and play with their siblings differently compared to how neuro-typical sibling dyads play with each other (Moyson & Roeyers, 2012). Understanding the sibling disability is important for the non-disabled sibling as it helps them understand the reasoning behind the different challenges and behaviors their sibling may display (Moyson & Roeyers, 2012). Non-disabled siblings

expressed the need for private time and to “not be a sibling for a while” (Moyson & Roeyers, 2012, p. 94). Researchers also noted that the non-disabled sibling’s acceptance of their sibling’s disability impacted their overall well-being (Moyson & Roeyers, 2012). The quality of life for the non-disabled sibling is not bad but could always be improved. Support groups and interventions are just a few ways to improve the well-being of the neuro-typical child.

Being in a support group with peers who understand the challenges of being the non-disabled sibling has positive implications on the overall sibling relationship quality (Carter et al., 2016; Dodd, 2004; Evans et al., 2001; Scelles et al., 2012). During support groups, non-disabled siblings were able to understand their sibling’s disability and express the positives of having a brother or sister with a disability (Dodd, 2004; Evans et al., 2001). Non-disabled siblings could also express the negatives that come with having a sibling who has a disability (Dodd, 2004; Vatne & Zahl, 2017). One negative that was shared by all non-disabled siblings was how challenging behaviors displayed by their siblings can hurt their relationship (Dodd, 2004; Carter et al., 2016). For example, getting physically hurt was a common behavior that was talked about by siblings (Dodd, 2004; Carter et al., 2016). Children’s views about their siblings were overall positive, but children who had a sibling diagnosed with ASD had more negative views about their sibling (Dodd, 2004).

Research declares that support groups are beneficial for non-disabled sibling as it gives them the resources to talk to other peers about the challenges, they have with having a sibling with a disability. Non-disabled siblings are at a risk for emotional distress and deserve the focused attention and support necessary for their healthy development and maturation (McCullough & Simon, 2011). Post-support group surveys have shown there was an increase in sibling involvement and increased self-esteem for the non-disabled sibling (Evans et al., 2001).

Support groups help psychologically for the non-disabled sibling, by giving them sources to help with their mental health (Scelles et al., 2012). Health care professionals and parents are satisfied with group sessions, as they provide an opportunity for the non-disabled sibling to show their interest in the sisters' and brothers' disabilities (Scelles et al., 2012). Parents believe that accompanying brothers and sisters to a support group session offers a chance for parents and the non-disabled sibling to spend more time together (Scelles et al., 2012).

Interventions, like support groups, are a good resource to improve sibling relationship quality throughout the lifespan. Hayden et al. (2019) examined an intervention called SIBS talk and evaluated its effectiveness. SIBS talk is a ten-session, one-to-one intervention approach for schools to complete with children who have a brother or sister with a developmental disability (Hayden et al., 2019). Overall, the intervention had a small but positive impact on the children and their siblings who participated in the intervention.

SIBS talk intervention focused primarily on child siblings, while Lee and Burke (2021) did a pilot program intervention that looked at adult siblings and future planning for the sibling with the disability. Their pilot program produced many positive impacts on the adult sibling relationship. First, the program increased the communication between the siblings, as well as increased the involvement with the sibling who had a disability (Lee & Burke, 2021). Second, the intervention increased the knowledge and understanding of the different disabilities (Lee & Burke, 2021). Finally, there was an increase in empowerment and respect towards disability services (Lee & Burke, 2021). The SIBS talk intervention provided a positive experience for both siblings.

Throughout Emerging Adulthood

Transitioning from adolescence to emerging adulthood changes the sibling relationship and can impact the quality of the relationship, especially for those with disabled siblings.

Emerging adults' siblings can see the positives of having siblings with a disability, specifically autism (Carter, Carlton, & Travers, 2019; Travers, Carlton, & Carter, 2020). In the Travers et al. (2020) study the emerging adult participants described their siblings as being kind to others, caring, and having a sense of humor and identified these factors as positives. At the same time, they identified not being able to communicate effectively, challenging behaviors, and not living with their sibling as negatives. This limitation can impact time spent with the sibling and the overall quality of the relationship.

In the same study (2020) the results showed that emerging adults with siblings who have a disability spend time in many different activities, like those whose siblings are not disabled (Travers et al., 2020). These activities with siblings primarily take place within the home setting more so than community settings. Age, gender, and diagnosis of a specific disability can have an impact on the socialization of the siblings during the home setting activities and can impact the overall relationship quality. For example, when a larger age gap is present there are fewer activities done with the sibling with the disability. Travers et al (2020) also stated that males are more likely to have fewer interactions with their siblings.

Jacobs & MacMahon (2016) noted in their research, during adolescence, siblings realize that they may have to take on a care-taking role. When transitioning into the caretaker role during emerging adulthood, siblings can feel isolated from peers. Emerging adults found little outside support from care facilities, which increased concern for their siblings and their futures.

When it comes to mental health, siblings had higher levels of depression and anxiety during emerging adulthood (Sommantico et al., 2019). Also, adult siblings had lower life satisfaction compared to typically developed siblings (Sommantico et al., 2019). Specifically, individuals with a sibling diagnosed with ASD (autism syndrome disorder) had higher levels of depression compared to other young adults with siblings of other disabilities (Sommantico et al., 2019). These results are very similar during early childhood (Marquis et al., 2019).

Theoretical Framework

To help understand sibling relationships and how they change during the transition period of emerging adulthood, this study used Arnett's theory of Emerging Adulthood. This theory was also a guide in understanding the dynamics of having a sibling with a disability during this transitional period.

The theory of emerging adulthood was proposed by Arnett in 2004 (Arnett, 2007) and discusses the transitions and development tasks of emerging adults ages 18-25 (Arnett, 2000; Arnett, 2007). Arnett later extended the ages of emerging adults to 18-30 because of changes to societal norms about marriage and because of the increase in life expectancy (Arnett, 2007). During the transition from adolescence to adulthood, Arnett proposed five distinctions of emerging adulthood, which include: (a) age of identity explorations, (b) age of instability; (c) age of self-focus; (d) age of feeling in-between; and (e) age of possibilities (Arnett, 2000; Arnett 2007). During this transition, emerging adults are trying to find their place in the adult world (Arnett, 2007).

A key feature of emerging adulthood is identity exploration. This gives an individual the opportunity to explore different "identity markers" consisting of, but not limited to, higher education, different career options, an increased time of dating, and exploring different world

views (Arnett, 2000). During emerging adulthood, the overall well-being of an individual improves with some of the benefits including self-focused activities and individuals moving toward self-sufficiency (Arnett, 2007). Self-focused activities are increased during this time because an individual moving out of their childhood homes (Arnett, 2000; 2007).

Emerging adulthood also is not heterogeneous, meaning that not everybody goes through the same life events and each life event can happen at different stages of emerging adulthood (Arnett, 2007). Using this theory and applying it to this current study help clarify how having a sibling with a disability impacted the transitional period of emerging adulthood.

Purpose of the Study

The primary purpose of this study is to examine the positive aspects of sibling relationships when one sibling has a disability. The second purpose is to contribute to previous literature by using a self-perspective lens on the experience through the lens of an emerging adult.

CHAPTER 3: METHODS

The current study is concerned with understanding the impact disabilities have on sibling relationships during childhood and emerging adulthood. To fully comprehend the impact, mixed methods research design was used to, (1) to produce rigorous and robust results on the social problem (Headley & Clark, 2020) and (2) to cross-validate the findings of the study (Bergman (2011).

Participants

Participants included 73 siblings of individuals with a disability. To be included in the study, the sibling respondent must have been 1) currently living in the United States, 2) be an emerging adult (ages 18-30), and 3) have a sibling with a disability. The CDC definition of disability (2020) is “any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions)” (CDC, 2020, paras. 1). Diagnoses included in the survey were Autism Spectrum Disorder, Down Syndrome, Cerebral Palsy, ADHD, Hearing Loss/ Deaf, Intellectual Disability, Sickle Cell Disease, Fragile X Syndrome, and Fetal alcohol syndrome. Participants also had the option to select “other” and enter the correct diagnosis that described their sibling’s disability.

Procedure

After receiving IRB approval, the researcher started participant recruitment by using convenience sampling method. The current study targeted specific sibling support and disability advocacy groups through social media. A flyer was posted on different social media platforms like Facebook, Instagram, and LinkedIn (See Appendix D). Several Facebook, Instagram, and LinkedIn groups related to siblings or disabilities, such as “Autism Sibling Support Group,”

“Disability and Awareness Group,” and “The Sibling Support Project,” were used during the recruitment stage. The same flyer was used to recruit East Carolina University (ECU) students, which increased participants meeting the demographics needs for the current study.

All participants gave informed consent before completing the survey and were made aware that they were free to cease participation at any time. The first part of the survey included the Lifespan Sibling Relationship Scale (LSRS), where the participants were able to comment on their sibling relationship during childhood and currently. The second part included open-ended questions that allowed respondents to expand upon the positive aspects of having a sibling with a disability. The survey was open for two weeks to allow enough time to get an appropriate number of responses.

Measures

Socio-demographic

Participants provided basic socio-demographic data (e.g., age, gender, birth order, sibling’s age and gender, sibling’s diagnosis, and number of siblings) via the questionnaire (See Appendix B).

Lifespan Sibling Relationship Scale

The Lifespan Sibling Relationship Scale (LSRS) to measure how sibling relationships changed throughout the lifespan (Riggio, 2000) (See Appendix C). The LSRS helped the researcher to understand how the disability impacts the sibling relationship. First, the Adult Affect section assessed the emotions that the sibling has towards their sibling with a disability (8 items, e.g., “My sibling makes me happy,” “I am proud of my sibling,” “My sibling makes me very angry”). Second, the Adult Behavior section helped the researcher understand the communication between the siblings (8 items, e.g., “I call my sibling on the telephone

frequently,” and “I never talk about my problems with my siblings”). The Adult Cognition section (8 items, e.g., “My sibling is very important in my life,” and “I know that I am one of my sibling’s best friends”), measured sibling relationship quality. The Child Affect section (8 items, e.g., “I enjoyed spending time with my sibling as a child,” and “My sibling bothered me a lot when we were children”), contributed to understanding sibling relationship quality. Next, the Child Behavior section helped analyze sibling behaviors during interaction with each other (8 items, e.g., “My sibling and I shared secrets,” and “My sibling and I helped each other when we were children”). Finally, the Child Cognition section (8 items, e.g., “My sibling had an important positive effect on my childhood”), measured how positive their relationship was with the sibling who has the disability. The participants responded using a Likert-type scale ranging from 1 (“Strongly Agree”) to 5 (“Strongly Disagree”). The reliability of this measure in the current study has a Cronbach alpha score of .93, which makes LSRS reliable.

Strengths in Sibling Relationship

Open-ended questions were structured around the positive aspects of having a sibling with a disability (e.g., “What positive aspects did you gain from having a sibling with a disability?”, “What positive qualities did you gain from your sibling?”). Respondents were able to share their overall experience of having a sibling with a disability (e.g., “Overall, what was your experience with your sibling?” and “What is one best memory you shared with you sibling?”) (See Appendix C). Additionally, participants described the similarities and difference they saw when comparing their relationship to a typical sibling relationship (e.g., “What is similar about your relationship with your sibling compared to typical sibling relationships?”). Finally, the last question asked respondents to include any other additional information that was not included in

survey (e.g., “Is there any other part of your sibling relationship you would like to share that was not included in this survey?”).

Data Analysis

The survey responses were collected electronically utilizing Qualtrics. The responses were downloaded into an Excel file and uploaded into the statistical program SPSS (IBM SPSS Statistics for Windows, Version 28.0) for analysis. The researcher utilized both full and partial responses to fully comprehend the magnitude of how disability impacts sibling relationships.

Three analytical methods were used to analyze the data, which included frequency, regressions, and thematic analysis for the open-ended questions. Using Frequency analysis help examine values of a variable phenomenon, such as seeing how participants viewed their sibling relationship during childhood and emerging adulthood (See Table 1). Second, a multiple regression analysis was used to help analyze the impact that childhood relationships had on adult relationships (see Table 1). To properly run the multiple regression analysis and for the data to be effectively plugged into SPSS, the data from the LSRS subscales that focused on the adult relationship (Adult Affect, Adult Behavior, and Adult Cognition) was combined into one score, represented as Adult Net score (combined). The same was done with the subscales the contained the childhood relationship (Child Affect, Child Behavior, and Child Cognition), represented by Child Net score (combined). The Adult Net score (combined) was used as the dependent variable and the Child Net score (combined) and other demographics (gender, race, and birth order) as independent variables.

The current study used participant demographics to help understand how race, gender, and birth order can impact a sibling relationship. The researcher used frequency analysis to find the means and percentages of race, gender, and birth order of each participant (See Table 1).

Then the researcher used those findings to help compare the variables of quality time spent with their sibling and overall experience they shared with their sibling during both childhood and emerging adulthood. Next the current study ran two different regressions on both Adult Net score (combined) and Child Net score (combined) against birth order, race, and gender to see how those demographics impacted the sibling relationships.

Finally, to analyze the open-ended question thematic analysis was used to interpret the responses from each participant. After collecting the responses, the researcher coded each response, did multiple rounds of re-coding the responses, then grouped codes according to themes, then interpreted those to come up with my end results. The responses and codebook were sent to a second coder. The second coder is a trained graduate student from East Carolina University department of the Human Development and Family Science department. She has experience with coding interviews and open-ended qualitative data related to disabilities. The second coder used the codebook as a guide and proceeded to code, recode, and grouped the codes into themes. Then re-analyzing the second coder's interpretations of the responses, the researcher compared the second coder's themes against the original code book and used the similarities in the results. A second coder was used to ensure the validity of the study and eliminate any research bias.

Table 1*Plan of Analysis*

Research Questions	Survey Questions	Statistical Test	Rationale
1. What are some differences in sibling relationship when one has a disability from childhood to emerging adulthood based on the Lifespan Sibling Relationship Scale?	23,25,27,28,29,3,42,43,44,45	Frequency Regression	Frequency- Used each subscale mean of the LSRC to help compare the sibling relationship differences in childhood and emerging adulthood Regression- Used combined subscale scores to help determine the impact that childhood relationships have on adulthood relationships.
2. How do demographic factors (e.g. birth order, gender, race) influence sibling relationship when one has a disability?	6,7,17,23,25,27,28,29,31	Frequency Regression	Frequency-Used the means of race, gender, and birth order to help compare if disability impacts more during childhood or emerging adulthood. Regression- Used combined subscale scores from LSRS against the demographics (birth order, race, and gender)
3. What are the positive aspects of having a sibling with a disability?	Open-ended questions (1-4)	Thematic Analysis	Determined themes in positive aspects the sibling relationship and across participant experiences

CHAPTER 4: RESULTS

This study focused on sibling relationships and how disability impacts the overall quality of them when one sibling has a disability. Using a mixed-methods approach, the researcher used a survey with open-ended questions to help understand the impact of disabilities on sibling relationships to answer the following research questions: (a) How does having a sibling relationships when one has a disability from childhood predict the sibling relationship during emerging adulthood based on the Lifespan Sibling Relationship Scale?; (b) How do demographic factors (*e.g.*, birth order, gender, race) influence sibling relationships when one has a disability? and (c) What are the positive aspects of having a sibling with a disability?

Participants

There was a total of 98 people who responded to the survey. Out of those 98, only 72 participants met the inclusion criteria. For example, people stated that they did not have a sibling with a disability or did not live in the United States, so their responses were removed from the final data set. Out of the 72 qualified participants, the researcher decided to use partial responses, which varied the number of participants and responses for each question. Using both partial and full responses were used to get the full picture of how disabilities impacted sibling relationships.

Most of the participants were female (76%), while only 16% were males (see Table 2). There were also five other participants (8%) who identified as genderqueer or nonbinary. For age, the majority were in the age range of 18-22, with 13 participants being 18 (25%), seven of the participants being 19 (13%), and nine of the participants being 22 (17%) years old (see Table 2). Twelve of the participants were in the age range of 23-26. Finally, there were eight participants who were in the age range of 27-30 (see Table 2). Most participants identified their

race/ethnicity as White (87%), with only four percent identifying as Black or African American and four percent having two or more races (see Table 2). Not included in the majority were Asian (3%), and one participant opted to not disclose their racial identity. Respondents represented all five regions of the United States, with most coming from the Southeast (36%) and Midwest (30%) (see Table 2). The remaining participants came from the Northeast (20%), West (8%), and Southwest (6%).

The participants were also asked about their siblings. When reporting on the number of siblings, most participants had either one (29%), two (32%), or three (25%) siblings. The other nine participants had four (5%) or more (9%) siblings. Survey participants also reported on their sibling's disability type, with a majority selecting the "other" category (34%) because their sibling's disability was not included on the predetermined list. For the "other" category, the participants entered several diagnoses including Small Brain Syndrome, Borderline Personality Disorder, Epilepsy, Chiari Malformation, Diabetes, Visual Impairment, Asperger, Spina Bifida, ADD, PTSD, Ehlers-Danlos, Mental Health (Bipolar, Anxiety, Depression), Speech Impediment, Sensory Processing Disorder, and Spinal Muscular Atrophy. Autism Spectrum Disorder (ASD) was the second highest diagnosis selected with 28% of the participants identifying that their sibling had ASD. The third highest sibling diagnosis was Intellectual Disabilities (18%). Other participants selected Down Syndrome (17%), ADHD (17%), Cerebral Palsy (9%), Hearing Loss/Deaf (6%), Sickle Cell Disease (2%), and Fetal Alcohol Syndrome (2%). Finally, participants were asked how they were related to their sibling with a disability. Most survey participants (82%) were biologically related to their sibling. The second highest choice selected by the participants was having an adopted sibling with a disability (8%). Five percent of participants stated that their sibling was their stepsibling and 5% stated that their sibling was a half-sibling.

Lastly, 2% of participants shared that their sibling was related to them through the foster care system.

Table 2

Characteristics of Participants

Characteristics	n	%
Gender of Respondent (n=67)		
Female	51	76
Male	11	16
Other*	5	8
Age of Respondent (n=53)		
18	13	25
19	7	13
20	2	4
21	2	4
22	9	17
23	2	4
24	2	4
25	5	9
26	3	6
27	1	2
28	4	8
29	1	2
30	2	4
Race of Respondent (n=67)		
White	58	87
Black or African American	3	4
American Indian or Alaska Native	0	0
Asian	2	3
Native Hawaiian or Pacific Islander	0	0
Other	0	0
2 or more races	3	4
I do not want to disclose	1	1

Note. Other*=Includes Genderqueer, Nonbinary, and other

Table 2 (continued)*Characteristics of Participants*

Characteristics	n	%
Current Location (n=66)		
Northeast	13	20
Southeast	24	36
Midwest	20	30
Southwest	4	6
West	5	8
Number of Siblings (n=65)		
1	19	29
2	21	32
3	16	25
4	3	5
More than 4	6	9
Sibling's Disability (n=65)		
Autism Spectrum Disorder	18	28
Down Syndrome	11	17
Cerebral Palsy	6	9
ADHD	11	17
Hearing Loss/ Deaf	4	6
Intellectual Disability	12	18
Sickle Cell Disease	1	2
Fragile X Syndrome	0	0
Fetal alcohol syndrome	1	2
Other**	22	34
Birth Order (n=65)		
Younger	29	45
Older	34	52
Twin	2	3
Related to Sibling (n=65)		
Biologically	53	82
Stepsibling	3	5
Half-Sibling	3	5
Adopted	5	8
Fostered	1	2

Note. Other ** = Includes Small brain syndrome, Borderline Personality Disorder, Epilepsy, Chiari Malformation, Diabetes, Visual Impairment, Asperger, Spina Bifida, ADD, PTSD, Ehlers-Danlos, Mental Health (Bipolar, Anxiety, Depression), Speech Impediment, Sensory Processing Disorder, Spinal Muscular Atrophy

Childhood Sibling Relationship Impact on Adulthood Sibling Relationships

Using the first research question, “How does having a sibling with a disability during childhood predict the sibling relationship during emerging adulthood based on the Lifespan Sibling Relationship Scale?”, multiple analyses were used to help understand if childhood sibling relationships, where one sibling has a disability, can predict adult sibling relationships. After running the regression where the dependent variable was Adult Net scores (combined) and the independent variables were Child Net score (combined) and demographics (race, birth order, and gender), there were a few predictors of adult sibling relationships. A multiple regression was used to predict the impact of demographics (birth order, gender, and race) and childhood sibling relationships on adult sibling relationships. The model explained a statistically significant amount of variance in adulthood relationships, $R^2=.49$, $F(4, 49)=11.67$, $p=.001$. Childhood relationships were a significant predictor of adulthood relationships, $b=.66$, $t(49) = 6.394$, $p=0.000$. The results also showed that race was a significant predictor of adulthood relationships $b= -0.21$, $t(49) = -2.03$, $p=0.05$.

Table 3

Childhood Relationships and Demographics Impact on Adult Relationships

<i>Variables</i>	<i>Estimate</i>	<i>SE</i>	<i>95% CL</i>		<i>p</i>
			<i>LL</i>	<i>UL</i>	
Constant	0.121	0.188			0.521
Child Net Score (Combined)	0.775	0.121	.382	.888	0.000*
Gender	0.011	0.042	-5.058	2.782	0.787
Race	-0.062	0.031	.497	6.329	0.048*
Birth Order	0.050	0.092	-15.038	3.031	0.591

Dependent Variable: Adult Net Score (Combined)

* $p < .05$. ** $p < .01$. *** $p < .001$

In addition to regression analyses, running frequencies helped with understanding whether childhood sibling relationships were a good predictor for adult sibling relationships where one sibling has a disability. The researcher used the overall Net Score of each subscale (Adult Affect, Adult Behavior, Adult Cognition, Child Affect, Child Behavior, and Child Cognition) to help analyze the impact that childhood sibling relationships had on adulthood sibling relationships. The results showed that when comparing the overall Adult Affect score with the overall Child Affect, more participants stated feeling strongly towards their sibling during adulthood (88%) than they did in childhood (81%). Similar results showed that participants stated that their relationship quality during adulthood (78%) was slightly better than in childhood (73%). The most notable difference was in comparing Adult Behavior and Child Behavior. The findings show that most participants felt communication decreased during adulthood, with 71% of participants stating that they communicated more with their sibling during childhood.

Finally, to help understand how childhood sibling relationships could be a predictor of adulthood sibling relationships, the researcher asked participants to rate their overall experience with having a sibling with a disability in both childhood and adulthood and to share how much quality time was spent daily with that sibling during childhood and adulthood. The findings showed that during childhood, nearly one-third (29%) of the participants stated spending more than 8 hours daily with their sibling. When rating their overall experience of having a sibling with a disability during childhood, the majority (67%) of participants said that they had a positive experience. They were asked to also share the time spent daily with their sibling currently during adulthood. Nearly half of the participants (41%) stated they did not spend time

with their sibling daily. However, results show that the majority (76%) of the participants reported currently having a positive relationship with their sibling.

Demographic Influence on Childhood and Adulthood Sibling Relationships

The second research question focused on, “How do demographic factors (e.g., birth order, gender, race) influence sibling relationships when one has a disability?” A regression analysis was used to help understand the-relationship between demographics, such as birth order, gender, and race, and the impact on both childhood and adulthood relationships. Following the regression analysis, the researcher used frequency to further examine how demographic factors impacted the sibling relationship in both childhood and adulthood.

Childhood Sibling Relationships

A multiple regression was used to predict the impact of birth order, race, and gender on sibling relationships during childhood. The results showed that there was no statistically significant relationship between the demographics (birth order, race, and gender) and childhood relationship, $R^2 = .0$, $F(3,50) = .07$, $p = .977$ (see Table 4). However, after running frequency analysis, there were some notable results that emerged when specifically looking at how birth order, race, and gender impacted sibling relationships during childhood.

Birth Order. Overall, there were more older sibling participants ($n=32$) than younger sibling participants ($n=29$). Only two participants identified as a twin of their sibling with a disability. Of the younger sibling participants ($n=29$), 34% spent more than 8 hours daily with their sibling who had a disability during childhood. While among older siblings ($n=32$), only 25% spent more than 8 hours daily and 28% spent 3-4 hours daily during their childhood. Regarding the overall experience during childhood, of the older sibling participants ($n=32$) nearly half (47%) had a positive experience with their sibling with a disability during childhood.

Similarly, 45% of the younger sibling participants (n=29) also stated having a positive experience during childhood.

Race/Ethnicity. White siblings were more likely to spend more than 8 hours a day with their disabled sibling daily (n=54; 30%) compared to their African American counterparts (n=4; 0%). African American participants noted spending less time with their sibling during childhood than other participants, with one-third (33%) of them saying they spent no time with their sibling. Participants who identified as Asian American or two or more races also spent more than 8 hours daily with their sibling who has a disability. Looking at the overall quality of their sibling relationship during childhood (n=63), White siblings (n=25; 46%) had a more positive experience than other participants.

Gender. Comparing the time spent with their sibling with a disability, nearly one-third of females (30%) spent more than 8 hours daily during their childhood with their sibling with a disability, while one-third of males (36%) spent 3 – 4 hours daily during childhood with their sibling with a disability. When considering the quality of their relationship during childhood, 47% of females said that their experience with their sibling was more positive than negative. Males also agreed with the females that they had positive experiences with their sibling. Eight of 11 of the participants (76%) stated that they had positive experiences with their siblings.

Table 4*Demographics Impact on Childhood Sibling Relationships*

<i>Variables</i>	<i>Estimate</i>	<i>SE</i>	<i>95% CL</i>		<i>p</i>
			<i>LL</i>	<i>UL</i>	
Constant	0.333	0.214			0.126
Gender	0.017	0.049	-5.180	4.039	0.734
Race	-0.010	0.036	-4.749	2.042	0.775
Birth Order	0.011	0.108	-6.328	14.714	0.922

Dependent Variable: Child Net Score (Combined)

* $p < .05$. ** $p < .01$. *** $p < .001$

Adulthood Sibling Relationships

A multiple regression with enter method was used to predict if birth order, race, or gender impacted sibling relationships during emerging adulthood. The results showed that there was not a statistically significant relationship between the demographics (birth order, race, and gender) and adult relationship, $R^2 = .06$, $F(3,53) = 1.13$, $p = .344$ (see Table 5). However, after running a frequency analysis, there were some notable results that emerged when specifically looking at how birth order, race, and gender impacted sibling relationships during adulthood.

Birth Order. Currently, both the younger ($n=28$; 43%) and older sibling participants ($n=29$, 41%) spent 0-2 hours daily with their sibling with a disability. When viewing their current relationship in emerging adulthood, both the older sibling participants (48%) and the younger sibling participants (43%) stated having positive experience with their sibling with a disability. Older siblings agreed to more of the positive survey statements about their sibling with a disability. Results showed that younger sibling participants agreed to having more communication with their sibling.

Race/Ethnicity. The study also compared time spent with the sibling with a disability (n=59). Both White siblings (n=21; 42%) and African American siblings (n=2; 67%) currently spend less time with their sibling with disability in emerging adulthood, compared to other racial sibling dyads. When asked about the overall quality of their current sibling relationship, White siblings (n=50; 50%) indicated their current relationship was positive, while African Americans (n=3; 33%), reported a positive relationship. There was a notable difference in the Lifespan Sibling Relationship Scale when participants rated if they presently spent time with their siblings. African American participants strongly disagreed with this statement (100%), while other races either strongly agreed or somewhat agreed with this statement (40%). Similar results were seen when asked to rate “My sibling and I do a lot of things together.” All the African American participants strongly disagreed with this statement, while only 16% of White participants disagreed with this statement.

Gender. Most of both females and males currently spend 0-2 hours daily with their sibling with a disability. Regarding their current relationship, 50% of the females (n=44) stated that their experience with their sibling was positive, while only 40% of males (n=10) stated that their relationship was positive or somewhat positive. When looking at current communication patterns, results showed that Males (44%) were more likely talk about their problems with their sibling with a disability compared to Females (8%).

Table 5*Demographics Impact on Adult Sibling Relationships*

<i>Variables</i>	<i>Estimate</i>	<i>SE</i>	<i>95% CL</i>		<i>p</i>
			<i>LL</i>	<i>UL</i>	
Constant	0.466	0.235			0.053
Gender	0.012	0.054	-6.000	4.162	0.822
Race	-0.074	0.040	-.871	6.650	0.073
Birth Order	0.036	0.120	-14.281	8.731	0.762

Dependent Variable: Adult Net Score (Combined)

* $p < .05$. ** $p < .01$. *** $p < .001$

Positive Aspects of Having a Sibling with a Disability

To answer the third research question, “What are the positive aspects of having a sibling with a disability?” participants were asked a series of open-ended questions about their sibling relationship and the positive qualities and aspects they gained from their sibling with a disability. When analyzing the open-ended questions, five major themes emerged: (1) empathy and patience, (2) quality time, (3) life and worldview perspective, (4) responsibility, and (5) advocacy.

Empathy and Patience

The first theme that emerged was gaining patience and empathy. Out of the 62 participants who answered, 27 suggested that learning empathy or patience from their sibling helped them in life. When talking about gaining patience, a younger female sibling participant stated “He makes me more patient & passionate about working with others. I love to [sic] him & miss him so much & I’m ready to move back home to be close to him.” A 25-year-old female participant briefly stated, “Higher empathy for people who are different.” An older female sibling participated stated how having a sibling with a disability made her more patient towards others, “I gained a positive outlook on life, and I feel I am more understanding and patient

towards others. I am less quick to judge before knowing all the facts.” Alongside gaining patience, participants expressed that they also gained empathy. Another stated, “Gives me more reason to be empathetic towards others. Finally, a male participant added, “I believe I gained a strong sense of empathy as well as being more cognizant of others who might be trying to live with their own disability.”

Quality Time with Sibling

The second major theme was being able to spend quality time with their sibling. Out of the participants who answered the open-ended questions 25 out of 62 participants noted that hanging out or being together was a positive aspect of having a sibling with a disability. When describing the experiences they shared with their sibling with a disability, a 18 year old participant stated,

At my dance recital every year, I would look for my sister, who was always sitting front row, cheering me on and clapping for me, she was always the first person I ran to after any accomplishment because I knew how proud she was of me.

In one example of how siblings would hang out with each other, an older sibling participant stated,

Talking one night till the sun came up and neither of us knew that it had been that long. This was after some really hard family events and we had been separated for the longest time ever. This was the first time she actually opened up to me about her disease and how she was feeling with it.

Going on vacations with their sibling was noted to be another experience that the neuro-typical sibling noted as a positive experience. A participants mentioned how their best memory was hanging out with their sibling while on vacation, the participant said,

The best memory I have is going on family vacations with my brother and we would ride in the car together, we would argue just like any other siblings would but we also had the best bonding moments on our long car rides.

Finally, playing with their sibling was stated by the participants as a positive aspect. There were many different scenarios explained by the participants stating how each sibling dyad played together. A twin female sibling participant stated, “We used to play a lot. I remember making a game out of ringing our toaster with him. The game was cute.” And another participant said, “Playing in the snow together when we were young.”

Life Perspective and Worldview

The third major theme was gaining new life and world perspectives. Eighteen out of 51 participants stated that they gained a new perspective in result of having a sibling with a disability. A biological female sibling participant person stated,

I got to grow up with a different perspective on life and people with disabilities. Most people judge when they see someone with a disability, but I’m the opposite. I love interacting with people with special needs because they’re the same as everyone else. It also helped me advocate for my brothers and others in the community.

Another female sibling stated,

As I got older I realized have a sibling with a disability gave me a completely different aspect on life that nobody I’ve ever met also has. I pride myself in

knowing that I have an advantage in life knowing that not everything is fair or perfect. Even though that may be true, there is always a positive in the life we live and we can't let the bad parts overtake us.

Participants also expressed positive perspective on disabilities and the importance of acceptance. For example, one participant said,

I love children and adults with disabilities. I am more understanding of others differences. I am more patient with others. I am able to be an advocate for anyone in the community. I know how to speak to people with disabilities properly. And most important of all, I see them as people, regular people. They might need help with cutting up their food or being understood when ordering at a restaurant, but they are aware of their decisions, they do need to be held accountable when they're doing something they shouldn't. They should be included and treated like anyone else.

Participants had an inclusive worldview by having a sibling with a disability. An 18 year old male participant shared their worldview, stating, "In my later years with her we formed a pretty strong bond, and it helped me get a wider worldview." Another participant said, "Broadened my worldview, and made me protective of someone. One person took a religious perspective of how to use their religion as a guide for how to treat others,

...Empathy towards other families with special needs children. Cultivation of love for anyone/everyone who had a disability of any sort. How to truly be fearless in life. How to love purely without a biased/hypercritical mindset. How to be patient with special needs people/elderly, How to be there for those who are looked at as

“weird” or “stupid” because of their special needs. How to live each day as it could be your last

Gaining Responsibility

In the fourth theme, participants noted a positive aspect was gaining responsibility through having a caregiver role. There were 11 participants out of 62 who noted specifically gaining responsibility through caregiving. One participant, whose sibling with a disability was fostered, talked about her experiences of being the caregiver of her sibling,

I was definitely (and still can be) in a large caretaker role despite the large age gap. Another thing would be the concept of her not aging mentally— which means her likes/dislikes never developed. Another difference would be the behavioral issues are still a thing (4-year-old mind) and she can't communicate the needs wants that cause the behavioral issues (ie; PMS, grieving, etc)

Another participant claimed, “I would “Watch” him on a regular basis. He couldn't be left alone for long.” Similarly, having to “parent” their sibling was a notable theme that emerged. One participant noted, “As I got older and older in certain situations I would have to "parent" my sibling and walk her step by step through different processes as well as speak for her in social situations.”

Advocacy

The last theme that emerged was being an advocate. Seven participants established that gaining advocacy was a positive aspect from their relationship with their sibling. A sibling mentioned, “I also am a lot more inclined to stick up for people in the moment, ever since I was a kid if anyone was being mean to them I'd come out swinging (metaphor).” Another sibling wrote, “I'm very good at looking after people due to taking care of my younger brother.”

One participant mentioned how having a sibling with a disability helped her to be an advocate for herself, she wrote,

My sister is very feisty, mostly because if she can't physically fight for herself she verbally can. Shes REALLY good at verbally fighting. She thought me how to speak up for myself and say how I feel because she could do it so easily.

Summary of Results

The first purpose of this study was to see if there was a relationship between childhood sibling relationships and adulthood relationships and how contextual factors (race, gender, and birth order) impacted both. The results showed there was a direct relationship between childhood relationships and adult sibling relationships. However, there was not a strong relationship between the contextual factors and both childhood and adulthood sibling relationships. The second purpose of this study was to establish whether there are positive aspects that come from having a sibling with a disability. The overall results showed that despite gender, race, and birth order, most participants stated that they have positive experiences with their sibling with a disability. They also stated that they gained positive aspects from having a relationship with a sibling with a disability during both childhood and adulthood.

CHAPTER 5: DISCUSSION

The current study explored how a disability can impact sibling relationships throughout emerging adulthood. There were three questions that guided the research of this study: (a) How does having a sibling with a disability during childhood predict the sibling relationship during emerging adulthood based on the Lifespan Sibling Relationship Scale? (b) How does demographic factors (*e.g.*, birth order, gender, race) influence sibling relationships when one has a disability? and (c) What are the positive aspects of having a sibling with a disability?

Childhood Sibling Relationships Impact on Adulthood Sibling Relationships

Looking at the first hypothesis, childhood sibling relationship can impact adult sibling relationships, where one sibling has a disability, the results overall confirmed this hypothesis. Two statistical tests, multiple regression and frequency, were run to understand how childhood sibling relationships could impact adult sibling relationships. The multiple regression results show that there is a direct relationship between childhood relationships and adulthood relationships. Results showed that childhood relationships were a significant predictor of adulthood relationships, $b = .66$, $t(49) = 6.394$, $p = 0.000$. Given that the probability was greater than .05, that indicated there was a statistically significant direct relationship between childhood and adulthood sibling relationships. Though not statistically significant, similar results came from the frequency data. For example, when rating how they felt about their sibling with a disability, more participants agreed that they had stronger emotions toward their sibling during adulthood (88%) than they did in childhood (81%). These results can be explained by the notion that during adulthood, sibling dyads are able to have deeper connections with their siblings with a disability than they are during childhood. The same results were showcased when asked about the quality of their relationship, both childhood and adulthood, with the sibling quality being

slightly better during adulthood (78%) than during childhood (73%). Having an increase, the quality of their relationships during adulthood, coincides with previous research done by Jensen et al., 2018. The overall findings add to previous literature on how having a sibling with a disability during childhood impacts the adulthood sibling relationship.

There was some outlier frequency data contradicting the multiple regression results that childhood relationships have a direct impact on adulthood relationships. The frequency results show that 71% of participants agreed that they had frequent interaction with their sibling during childhood. I expected based on the high frequency of interaction in childhood, the interactions with their sibling during adulthood would stay consistent or increase. However, during adulthood, only 50% of participants agreed with having frequent interaction and communication with their sibling currently. Although these findings contradict the regression results, these findings confirm previous literature from Jensen et al (2018) and Aldrich et al (2021), which showed that there is a decrease in interactions and communications during emerging adulthood. However, the frequency results showed that participants stated that their relationship quality with their sibling is more positive now than during childhood. Previous literature also confirms these results. Jensen and colleagues (2018) stated that there is an increase in closeness and quality of sibling relationships during emerging adulthood. One reason why the regression data and frequency data had contradictory results was may be due to how the regression data was entered. For the regression data, all sections pertaining to questions about their childhood relationships and adulthood sibling relationship were combined. In contrast, while running the frequency data the researcher used each section on both childhood and adulthood relationships separately.

Demographics Influence on Childhood and Adulthood Sibling Relationships

There was no direct relationship between demographics and both childhood and adulthood sibling relationships. After running a regression analysis on both childhood and adulthood sibling relationships there was no statistical significance on how different contextual factors (i.e., birth order, gender, race) impact the sibling's relationship. As a result, the demographics did not have a direct impact on sibling relationships pertaining to the participants in the current study. There could be many other contextual factors impacting these results. For example, geographical location of where the sibling dyads grew up could have impacted the relationship more than race, birth order, or gender. Because the current research did not look at all of the contextual factors that could impact both childhood and adulthood relationships, future research should focus on other contextual factors (i.e., geographical location, SES, or religion) and their impact on those relationships.

After running a regression analysis with Childhood Net score, race, gender, and birth order as independent variables and Adulthood Net score as a dependent variable, race was the only demographic that impacted adulthood relationships. There were frequency results, although not statistically significant, that supported these findings. For example, African American siblings (n=2; 67%) currently spend less time with their sibling with disability in emerging adulthood, than any other race. Other contextual factors (i.e., SES) could explain why African American siblings spend less time with their siblings during adulthood. McHale et al. (2012) research goes into more depth about how other sociocultural factors can impact sibling relationships. Another demographic survey response that could explain why African American siblings spent less time with their sibling was some of the participants stating having more negative experiences with their siblings whereas other White participants noted having more

positive experiences. White siblings (n=50; 50%) indicated their current relationship was positive, whereas only 33% of African Americans reported currently having a positive relationship. These results confirm previous literature that describe how being a minority can have a negative impact on sibling relationships based on the research done by McHale et al. (2012).

Positive Aspects of Having a Sibling with a Disability

The current study explored the positive aspects that come with having a sibling with a disability. Through the analysis of open-ended questions, the findings showed that there are positive aspects of having a sibling with a disability. In result there were five themes that emerged, empathy and patience, hanging out with their sibling, life and worldview perspective, gaining responsibility, and advocacy.

Most of the participants stated that they gained patience and empathy. Having these qualities, helped the participants throughout their life by having empathy and patience for others with and without a disability. Following patience and empathy, being able to hang out with their sibling was the second highest theme that emerged. The activities that were described by participants included going on vacations with their sibling, playing games with their sibling, going on car rides together, wrestling, and talking face to face or in person. Thirdly, having a different life perspective or worldview was another positive aspect mentioned. When describing have a new perspective of life, some participants mentioned how having a sibling with a disability made them more aware of how people are different. While others described their perspective of being a sibling to a person with a disability and how their life was different from their friends. The fourth positive aspect of having a sibling with a disability was gaining responsibility. Participants noted they gained responsibility by having care giving roles during either childhood or adulthood. Even

with the stress and weight of being a caregiver, many respondents (22%) stated that the positive that came out of that experience was maturing faster and learning how to be responsible. Finally, the last theme was gaining advocacy. Some participants specified that they had to advocate for their sibling growing up, which gave them the confidence to advocate for others who have a disability. Other participants expressed gaining advocacy for themselves after learning to advocate for their sibling with a disability.

Participant answers confirmed that there are more positive experiences than deficits when an individual has a sibling with a disability. These findings add to the current literature, because most of the previous literature does not emphasize the positive aspects one can gain from having a sibling with a disability. For example, previous literature explores how there is a decrease in mental and physical health for the sibling without the disability throughout childhood (Marquis et al., 2019a; Moyson & Roeyers, 2012). Similar literature explores the decrease in mental health of emerging adults when they have a sibling with a disability (Sommantico et al., 2019). For future research, it is important to focus on the positive aspects of having a sibling with a disability rather than just focusing on the deficits or challenges.

Conclusion

The current study focused on how disabilities impact sibling relationships. The first purpose of this study was to look at the positive aspects of sibling relationships when one sibling has a disability. The second was to provide a self-perspective lens on the experience through the lens of an emerging adult. In conclusion, disability does impact sibling relationships throughout the lifespan. During childhood, the results showed that not being able to feel close to their sibling, having to be the caregiver, and dealing with the characteristics of a disability negatively impacted the sibling relationship. However, participants stated that they still had positive

experiences with their siblings. During emerging adulthood, physical separation from their sibling with a disability hindered the quality of the relationship more than the disability itself. However, participants stated that currently they also experience positive experiences with their siblings. Overall, the results show that childhood sibling relationships can predict adulthood sibling relationships when one sibling has a disability.

Limitations

The current study adds to the research on how disability can impact sibling relationships throughout the lifespan. With that in mind, the current research still had some limitations that emerged. The first limitation was the sampling method that was used. The current study did not use the method of random sampling. Not using a random sampling method limited the access of having a larger population be represented in the data set. Also, having a niche population (e.g. sibling dyads where one sibling has a disability, while also currently living in the US) to extract the sample from, limited the number of responses of people who completed the survey. The second limitation was having participant bias. Participants could have been biased on many aspects of their sibling relationship, which could make their relationship look better than it is. Another limitation was not having a diverse population. Because most of the respondents were White (58 participants) and only having 10 participants from other racial/ethnic groups (three African American, two Asian, and three identifying as two or more races), the overall results did not provide a diverse cultural perspective.

Future Research

Future research that is focused on sibling relationships and how disability impacts that relationship should use a random sampling method, as this will increase the number of

respondents and increase validity of the study. Using random sampling will also allow future researchers to be able to apply their results to a broader population.

Furthermore, future research should do more analyze on the relationship types (i.e., biological, fostered, step, or half) and how that impacts the quality of the sibling relationship when one sibling has a disability. Being able to understand the differences between being biologically related to the sibling with a disability versus having been related through adoption or fostered. Also, future research should take into consideration the possibility that the sibling who is participating may also have their own disability that may change the results of how they view their relationship with someone else who has a disability or similar disability.

Finally, more research needs to be done on how professionals in the field can support the non-disabled sibling. Making sure that their needs are met, may decrease the likelihood of them feeling left out, not loved, lower mental illness, and much more. Understanding the needs of the non-disabled could help with building positive family dynamics.

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APPENDIX A: INSTITUTIONAL REVIEW BOARD APPROVAL



EAST CAROLINA UNIVERSITY
University & Medical Center Institutional Review
Board

4N-64 Brody Medical Sciences Building · Mail Stop 682
600 Moye Boulevard · Greenville, NC 27834

Office 252-744-2914 · Fax 252-744-
2284 · rede.ecu.edu/umcirb/

Notification of Exempt Certification

From: Social/Behavioral IRB

To: Kayla Bryant

CC: Sheresa Blanchard

Date: 3/9/2022

Re: UMCIRB 22-000266

UNDERSTANDING DISABILITIES WITHIN SIBLING RELATIONSHIPS

I am pleased to inform you that your research submission has been certified as exempt on 3/9/2022. This study is eligible for Exempt Certification under category # 2a.

It is your responsibility to ensure that this research is conducted in the manner reported in your application and/or protocol, as well as being consistent with the ethical principles of the Belmont Report and your profession.

This research study does not require any additional interaction with the UMCIRB unless there are proposed changes to this study. Any change, prior to implementing that change, must be submitted to the UMCIRB for review and approval. The UMCIRB will determine if the change impacts the eligibility of the research for exempt status. If more substantive review is required,

you will be notified within five business days.

Document	Description
Approved Thesis Proposal(0.01)	Additional Items
Approved Thesis Proposal(0.01)	Study Protocol or Grant Application
Consent for Study(0.03)	Consent Forms
Email Script (0.02)	Recruitment Documents/Scripts
Social Media Script (0.02)	Recruitment Documents/Scripts
Survey questions(0.01)	Surveys and Questionnaires

For research studies where a waiver or alteration of HIPAA Authorization has been approved, the IRB states that each of the waiver criteria in 45 CFR 164.512(i)(1)(i)(A) and (2)(i) through (v) have been met. Additionally, the elements of PHI to be collected as described in items 1 and 2 of the Application for Waiver of Authorization have been determined to be the minimal necessary for the specified research.

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

APPENDIX B: CONSENT FORM AND INCLUSION CRITERIA

Consent Form:

You are being invited to participate in a **research** study titled “Understanding Disability Within Sibling Relationships Through Emerging Adulthood” being conducted by Kayla Bryant, a graduate student at East Carolina University in the Human Development and Family Science department. The goal is to survey 100-300 individuals in/at East Carolina University. The survey will take approximately 20-30 minutes to complete. It is hoped that this information will assist us to better understand how disabilities impact sibling relationship throughout the lifespan. Your responses will be kept confidential, and no data will be released or used with your identification attached. Your participation in the research is **voluntary**. You may choose not to answer any or all questions, and you may stop at any time. We **will not** be able to pay you for the time you volunteer while being in this study. There is **no penalty for not taking part** in this research study. Please note that participants should be 18 years old or older. If you are under the age of 18, please do not participate in this study.

Please call Kayla Bryant at 540-207-4019 or email at bryantka20@students.ecu.edu for any research related questions or the University & Medical Center Institutional Review Board (UMCIRB) at 252-744-2914 for questions about your rights as a research participant.

Disclaimer for Survey

For this survey, disability will be defined as “any condition of the body or mind (impairment that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions))”.

Does your brother/sister have a disability? (check one) Yes or No

Are you between the ages 18-30? (check one) Yes or No

Do you currently live in United States? (check one) Yes or No

Do you give consent for participation in this study? (check one) Yes or No

[If participant selects no to any of the questions above, they will not move on to the rest of the survey]

APPENDIX C: SIBLING RELATIONSHIP SURVEY

What is your age?

- 18
- 19
- 20
- 21
- 22
- 23
- 24
- 25
- 26
- 27
- 28
- 29
- 30

Gender (Please select one that best describes you)

Male

Female

Non-binary / Third Gender

Gender Neutral

Agender

Pangender

Genderqueer

Two-Spirit

Other _____

Prefer not to say

What race/ethnicity are you? (Choose one that best describes you)

White

Black or African American

American Indian or Alaska Native

Asian

Native Hawaiian or Pacific Islander

Other

2 or more Races _____

I do not want to disclose

What region of the United States do you live in?

Northeast (Connecticut, Delaware, District of Columbia, Maine, Maryland, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, Vermont, Virginia, and West Virginia)

Southeast (Alabama, Florida, Georgia, Arkansas, Kentucky, Louisiana, Mississippi, North Carolina, South Carolina, and Tennessee)

Midwest (Illinois, Indiana, Iowa, Kansas, Michigan, Minnesota, Missouri, and Nebraska)

Southwest (Arkansas, Colorado, Louisiana, Montana, New Mexico, North Dakota, Oklahoma, South Dakota, and Texas)

West (Alaska, Arizona, California, Hawaii, Idaho, Montana, Nevada, New Mexico, Oregon, Utah, Washington, and Wyoming)

How many sibling(s) do you have?

- 1
- 2
- 3
- 4
- More than 4

How many of your sibling(s) have a disability?

- 1
- 2
- 3
- 4
- More than 4

[Disclaimer] If you have more than one sibling with a disability, moving forward please choose only one sibling relationship when completing this survey. Thank You!

Are you the younger, older, or twin sibling to your sibling with a disability?

- Younger
- Older
- Twin

What is your sibling's disability? (Select all that apply)

- Autism Spectrum Disorder
- Down Syndrome
- Cerebral Palsy
- ADHD
- Hearing Loss/Deaf
- Intellectual Disability
- Sickle Cell Disease
- Fragile X Syndrome

Fetal alcohol syndrome

Other _____

How is your sibling with a disability related to you?

Biologically

Step-Sibling

Half-Sibling

Adopted

Fostered

Did you live with your sibling with a disability during your childhood?

Yes

No

How much time, on average, during your childhood did you spend with your sibling with a disability each day?

None

1-2 hours

3-4 hours

5-6 hours

7-8 hours

More than 8 hours

Rate your overall childhood experience with having a sibling with a disability.

	1-Positive	2-Somewhat Positive	3-Neutral	4-Somewhat Negative	5-Negative
Overall childhood experience	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Does your sibling with a disability live with you currently?

Yes

No

How much time, on average, do you currently spend with your sibling with a disability each day?

None

1-2hours

3-4 hours

5-6 hours

7-8 hours

More than 8 hours

Rate your overall experience as an adult with having a sibling with a disability.

	1-Positive	2-Somewhat Positive	3-Neutral	4-Somewhat Negative	5-Negative
Overall adult experience	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please describe one positive aspect of having a sibling with a disability.

Lifespan Sibling Relationship Scale

For each of the questions you will answer on scale from 1(“Strongly Agree”) to 5(“Strongly Disagree”).

Adult Affect

1. My sibling makes me happy.
2. My sibling’s feelings are very important to me.
3. I enjoy my relationship with my sibling.
4. I am proud of my sibling
5. My sibling and I have a lot of fun together.
6. My sibling frequently makes me very angry.

7. I admire my sibling.
8. I like to spend time with my sibling.

Adult Behavior

9. I presently spend a lot of time with my sibling
10. I call my sibling on the telephone frequently.
11. My sibling and I share secrets.
12. My sibling and I do a lot of things together.
13. I never talk about my problems with my sibling.
14. My sibling and I borrow things from each other.
15. My sibling and I “hang out” together.
16. My sibling talks to me about personal problems.

Adult Cognition

17. My sibling is a good friend
18. My sibling is very important in my life.
19. My sibling and I are not very close.
20. My sibling is one of my best friends.
21. My sibling and I have a lot in common.
22. I believe I am very important to my sibling
23. I know that I am one of my sibling’s best friends.
24. My sibling is proud of me.

Child Affect

25. My sibling bothered me a lot when we were children.
26. I remember loving my sibling very much when I was a child.
27. My sibling made me miserable when we were children.
28. I was frequently angry at my sibling when we were children.
29. I was proud of my sibling when I was a child.
30. I enjoyed spending time with my sibling as a child.
31. I remember feeling very close to my sibling when we were children.
32. I remember having a lot of fun with my sibling when we were children.

Child Behavior

33. My sibling and I often had the same friends as children.
34. My sibling and I shared secrets as children.
35. My sibling and I often helped each other as children.
36. My sibling looked after me (OR I looked after my sibling) when we were children.
37. My sibling and I often played together as children.
38. My sibling and I did not spend a lot of time together when we were children.
39. My sibling and I spent time together after school as children.
40. I talked to my sibling about my problems when we were children.

Child Cognition

41. My sibling and I were “buddies” as children.
42. My sibling did not like to play with me when we were children.

43. My sibling and I were very close when we were children.
44. My sibling and I were important to each other when we were children.
45. My sibling and I had an important and positive effective on my childhood.
46. My sibling knew everything about me when we were children.
47. My sibling and I liked all of he same things when we were children.
48. My sibling and I had a lot in common as children.

This section included opened ended questions.

1. What is the best memory you have with your sibling?
2. What are some positive qualities that you gain from having a sibling with a disability?
3. How was your relationship with your sibling similar to the “normal” or “typical” sibling relationships you observed during your lifetime?
4. How was your relationship with your sibling different to the “normal” or “typical” sibling relationships you observed during your lifetime?
5. Is there any other part of your sibling relationship you would like to share that wasn't included in this survey?

APPENDIX D: LIFESPAN SIBLING RELATIONSHIP SCALE

Lifespan Sibling Relationship Scale Items

1. My sibling makes me happy.
2. My sibling's feelings are very important to me.
3. I enjoy my relationship with my sibling.
4. I am proud of my sibling.
5. My sibling and I have a lot of fun together.
- 6.* My sibling frequently makes me very angry.
7. I admire my sibling.
8. I like to spend time with my sibling.
9. I presently spend a lot of time with my sibling.
10. I call my sibling on the telephone frequently.
11. My sibling and I share secrets.
12. My sibling and I do a lot of things together.
- 13.* I never talk about my problems with my sibling.
14. My sibling and I borrow things from each other.
15. My sibling and I 'hang out' together.
16. My sibling talks to me about personal problems.
17. My sibling is a good friend.
18. My sibling is very important in my life.
- 19.* My sibling and I are not very close.
20. My sibling is one of my best friends.
21. My sibling and I have a lot in common.
22. I believe I am very important to my sibling.
23. I know that I am one of my sibling's best friends.
24. My sibling is proud of me.
- 25.* My sibling bothered me a lot when we were children.
26. I remember loving my sibling very much when I was a child.
- 27.* My sibling made me miserable when we were children.
- 28.* I was frequently angry at my sibling when we were children.
29. I was proud of my sibling when I was a child.

30. I enjoyed spending time with my sibling as a child.
31. I remember feeling very close to my sibling when we were children.
32. I remember having a lot of fun with my sibling when we were children.
33. My sibling and I often had the same friends as children.
34. My sibling and I shared secrets as children.
35. My sibling and I often helped each other as children.
36. My sibling looked after me (OR I looked after my sibling) when we were children.
37. My sibling and I often played together as children.
- 38.* My sibling and I did not spend a lot of time together when we were children.
39. My sibling and I spent time together after school as children.
40. I talked to my sibling about my problems when we were children.
41. My sibling and I were 'buddies' as children.
- 42.* My sibling did not like to play with me when we were children.
43. My sibling and I were very close when we were children.
44. My sibling and I were important to each other when we were children.
45. My sibling had an important and positive effect on my childhood.
46. My sibling knew everything about me when we were children.
47. My sibling and I liked all the same things when we were children.
48. My sibling and I had a lot in common as children.

Note. * Reverse scored item. Items 1–8 reflect Adult Affect; 9–16 reflect Adult Behavior; 17–24 reflect Adult Cognitions; 25–32 reflect Child Affect; 33–40 reflect Child Behavior; and 41–48 reflect Child Cognitions.

The participants responded to a Likert-type scale ranging from 1 (“Strongly Agree”) to 5 (“Strongly Disagree”).

APPENDIX E: EXAMPLE OF FLYER USED FOR SOCIAL MEDIA

This flyer was posted on social media.



**Do You Have Sibling
With A Disability?**

THEN THIS SURVEY IS FOR YOU!

I am a graduate student at East Carolina University and I am conducting a research study to better understand the **positive aspects** of having a **sibling with a disability**.

If you meet the following criteria please consider taking this survey:

- Participants must be between the ages of 18-30
- Participants must currently live in the US
- Participants must have a sibling with a disability

For this survey, disability will be defined as "any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions)" (CDC,2020).

It only takes 15-20 minutes!

Thank You!